

Posters

13. Psychosocial issues

S115

262 Fear of Progression Questionnaire for caregivers of youth with cystic fibrosis (FoP-Q/C)

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Objectives: Fear of disease progression (FoP) in parental caregivers of minors with cystic fibrosis (CF) is associated with distress and adherence to treatment. Measures for FoP are available for adult patients and their partners, but so far not applicable for caregivers. We developed a caregiver form of the questionnaire to apply for parental caregivers and investigated its psychometric properties.

Methods: Sixteen items were derived from the existing versions of the questionnaire and from interviews with clinical experts in family-oriented psychosocial care. Psychometric properties were tested in a sample of 50 caregivers (M=38.4 years; SD=6.72; 86% female) being interested to participate in a web-based psychotherapy for highly distressed caregivers of minors with CF. Internal consistency and convergent validity to other measures of distress (anxiety, depression) as well as divergent validity (parental quality of life) and sensitivity for change were investigated.

Results: Internal consistency was indicated by Cronbach's $\alpha=0.88$, split-half reliability $r=0.82$ and odd-even reliability $r=0.92$. Moderate positive correlations with anxiety ($r=0.51$; $p<0.01$) and depression ($r=0.57$; $p<0.01$) were found, as well negative moderate correlations to quality of life ($r=-0.54$; $p<0.01$). A subgroup of 23 participants receiving the web-based cognitive behavioural intervention showed a significant decrease of FoP-score ($d=1.11$).

Conclusion: The preliminary psychometric results indicate excellent reliability and validity, as well as sensitivity to change. The instrument allows the assessment of FoP in clinical care and research. Further validation in larger samples is recommended.

264 Grandparental knowledge of cystic fibrosis treatment

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Objectives: To investigate grandparental involvement in the care of their grandchild with CF and their knowledge of treatment.

Methods: Grandparents attended an informative meeting at the Leuven CF center, with specialist talks by the pediatrician, nurse, dietician and physiotherapist. A questionnaire assessed their involvement in care and knowledge before and after the talks.

Results: Twenty-three grandfathers (GF) (mean age 64) and 30 grandmothers (GM) (mean age 63) of 25 children (mean age 7.2) participated. Many grandparents present care for their grandchild once a week or more (17 GM and 16 GF). Grandparents had received CF information from the parents (51%), the CF association (21%), the internet (18%) and other (10%, e.g. books). Table 1 shows a selection of knowledge questions and the percentage of correct answers before and after the talks.

Table 1. Knowledge of grandparents

Example item	% correct answers	
	Before talks	After talks
Correct use of antibiotics	64	92
Pulmozyme DNase	56	71
Caloric value of foods	56	92
Caloric need in CF	87	88
Antibiotics and physiotherapy	19	47
Cleaning of nebulizer	94	88

Conclusion: The informative meeting was well attended. Insufficient knowledge was often related to questions on 'use of antibiotics', 'DNase' and 'caloric value of foods'. Grandparents corrected their answers on the second questionnaire, showing the teaching value of the talks. Overall, grandparents' knowledge of CF treatment was adequate and they are actively involved in the care of their grandchild making them important partners for parents and CF teams.

263 Parents' understanding of genetic mutation and the implications for their child's CF

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Objectives: A major new development in CF treatment are drugs that target mutation class, so that potential benefits may not – at present – be available to all patients with CF. This may lead to CF being viewed differently by teams and families, as a number of conditions rather than one. This study explored the understanding of parents with young children with CF.

Methods: A short survey asking about knowledge of mutation type and class and the potential importance of this on symptoms and treatment was circulated to parents of young children (<5 years) with CF attending the Leeds Regional Paediatric unit.

Results: 22 parents completed the survey. Three knew both of their child's mutations, 16 knew one, 3 were unsure. 9 (32%) knew their child's mutation class. All knew that both parents were carriers of the CF gene. Most knew that mutation class had an impact on health and symptom severity in CF, though there was also confusion with around 1/3 of respondents unsure or believing it made no or little difference. 11 (64%) felt it might influence future treatment options, though 8 (36%) were unsure.

Conclusion: Many parents are broadly aware that mutation class may be important in terms of severity of CF and future treatment, though many do not know their child's mutation type. There is still some uncertainty amongst parents about how their child's mutation types will affect what treatments are available for them in the future.

265 Exploring the pre-hospitalisation needs of parents of children with cystic fibrosis

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Background: Cystic Fibrosis is a life-limiting illness, often requiring repeated hospital admissions in order to effectively manage symptoms. Hospitalisation can be stressful for patients and their families. Pre-admission information provision is crucial in establishing a good basis for patient satisfaction and cooperation.

Objectives: To explore whether families who were admitted to a UK Children's Hospital were adequately prepared for their child's hospital admission.

Methods: Twelve parents whose children had been admitted within the last two years for routine intravenous antibiotics participated in the study. Data were collected using semi-structured interviews, analysed using inductive thematic analysis.

Results: Four main themes emerged: feeling unprepared; a challenging environment; interactions with the medical team, and parental role in medical care: relinquishing control versus active participation. The findings demonstrate that parents need to receive preparatory information; addressing the medical, practical and psychosocial implications of admission. The results highlight the adverse effects of inadequate information on the hospital experience. Parents reported feeling unprepared for the ward and uncertain of their role in care. Parental uncertainty was exacerbated by perceived difficulties with parent-physician communication.

Conclusion: Admission to hospital can be a difficult experience. Providing adequate information is essential in reducing parental stress, influencing how future experiences are appraised and managed. Effective physician-parent communication and opportunities to participate in care will improve parental satisfaction.